



Defining Value in Oncology: Perspectives from Patients with Metastatic Breast Cancer

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Objective

Value, as described by the Institute of Medicine, is the “best care at lower cost.” Yet value may be differently interpreted among health care stakeholders (Porter, 2010). We explored the understandings of value among patients in the Cancer Experience Registry with a focus on metastatic breast cancer (mBC) for this presentation. By understanding how patients define value when considering their cancer experience, we can identify ways to bridge gaps between health care policy and practice.

Methods

Using the Cancer Support Community's Cancer Experience Registry, an online initiative to capture the experiences of those impacted by cancer, we asked patients the following question:

“When considering your cancer experience, how would you define value?”

We focused on patients with mBC (n = 769), because of these patients' likely high number of health interactions and consistency of cancer stage.

Two researchers coded open-ended responses in vivo by thematic category.

- Inter-rater reliability was 85%.

Code categories included:

Value = Personal	Value = Exchange	Other
• Existential, practical, relational benefit	• Health-specific	• No response
• Preference (i.e., something I want)	• Economic exchange	• Unclear response
• Guiding principle		• Indicated lack of understanding
		• Reported no value

Results

Patients averaged 56 years of age (SD = 9.91, range: 24-93)

Among the 769 mBC patients, responses were categorized as:

- 2.34% were unclear
- 2.73% reported “no value”
- 7.41% provided an exchange value type response
- 8.97% did not understand the question
- 38.4% provided a personal value type response
- 45.9% did not respond

(Note: Percentages total over 100% because some of the responses were double coded due to having more than one possible meaning.)



The Cancer Experience Registry is an online research initiative that captures the immediate and ongoing or changing social and emotional experiences of cancer survivors and their caregivers. The Registry is for all cancer survivors and caregivers, but also includes 9 disease specific surveys including mBC.

- Patients and caregivers share their social and emotional experiences of cancer
- Data is analyzed and disseminated toward the goal of improving the lives of those experiencing cancer
- Findings contribute toward advancing research, care and policy

Over 7,600 cancer survivors and caregivers are registered in the Cancer Experience Registry.

Learn more or join the Registry at www.CancerExperienceRegistry.org

Findings in Depth

38.4% provided a personal value type response

Personal value responses fit into the following categories:

- Existential, practical, relational benefit: 25.4% (quotations follow)
 - “I learned to cherish every day and know who my friends are.” (Relational and Existential)
 - “Even the worst days are wonderful, because I got to help my son through a tantrum or watch cartoons with him when I was too tired to do anything else. But the best days are always tinged with melancholy, because I am constantly aware that they will soon become just a memory, and I can't be assured of how many more there will be. I suppose it's true that anything that's of true value is hard won.” (Relational and Existential)
 - “Information and appropriate communication of that information at the right time and right place.” (Practical)
- Preference: 8.06% (quotations follow)
 - “Quality of life”
 - “Value = comfort”
- Guiding principle: 4.94% (quotations follow)
 - “Live with no limitations”
 - “Whatever is going to give me integrity”

7.41% provided an exchange type response

Exchange value responses fit into the following categories:

- Economic exchange: 1.95% (quotation follows)
 - “Value is something positive a person gains from an organization or another person and value should always EXCEED any dollar amount paid.”
- Health-specific: 5.46% (quotations follow)
 1. “Value is best measured in emotional terms - what your care team and your supporters bring to the journey. It's doctors, nurses, and other health care professionals going beyond the science to reach out and touch you as a human being. Feeling that happening is worth much, much more than its weight in gold.”
 2. “Value=great medical care, a strong relationship with your oncology team and an oncologist willing to listen to your concerns, whether it be treatment concerns, financial concerns or emotional concerns.”
 3. “I would define value as my warm and caring association with my healthcare team.”
 4. “Value in cancer treatment is getting the best options at the lowest cost, presented to you in a manner that is easily comprehended.”
 5. “Effective results of treatment plan are first.”

Of those with a health-specific response (n=42), most (76.2%, n=32) described treatment benefit as being engaged by or feeling close to their health care provider (HCP) (as in quotations 1-3, above), while financial cost relative to benefit, or treatment efficacy (as in quotations 4-5, above) was mentioned rarely (n=7).

Conclusion

“Value” is multivalent; only 5.46% of patients with mBC in our sample conceived value as having any exchange-based meaning specific to health. When defining value relative to health care, patients emphasized the importance of their relationship with HCPs rather than the benefit of cost-effective treatment. Although quality, efficiency, and cost transparency in value-based care are essential, patients may be more focused on quality care as it relates to the HCP–patient relationship than on value relative to efficiency/cost. Patient engagement can help build on patients' focus on value as relationship, while promoting the principles of the Value Initiative.

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References

Porter, M. (2010). What Is Value in Health Care? The New England Journal of Medicine, 363: 2477-2481.